Lyme Disease Advisory Committee
Minutes of the October 24, 2000, Meeting
Department of Health Services, Sacramento

The first meeting of the Lyme Disease Advisory Committee (LDAC) was held on October 24, 2000, in Sacramento, California.

Committee members present:
Jean Hubbard, Lyme Disease Resource Center
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Lee Lull, Lyme Disease Support Network
Susie Merrill, Lyme Disease Support Network
Scott Morrow, M.D., California Conference of Local Health Officers
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

Committee member absent:
Alan Barbour, M.D., University of California, Irvine, was unable to attend the meeting.

Guests:
Lucia Hui, Department of Health Services
Anne Kjemtrup, D.V.M., Ph.D., Department of Health Services
Robert Murray, Ph.D., Department of Health Services
Rachael Tayar, Ph.D., Department of Health Services
James Tucker, Department of Health Services

1. Welcome and Introductions

Dr. Kramer called the meeting to order at 10:05 a.m. She introduced Dr. Tayar, the facilitator for the meeting. Committee members and guests introduced themselves. Dr. Kramer described the involvement of the Department of Health Services (DHS) guests with the Department's Lyme Disease Program. Dr. Murray has been responsible for evaluating physician-submitted Lyme disease reports. Ms. Lucia Hui has been involved in Lyme disease research and the Lyme disease community, and Dr. Anne Kjemtrup serves as the liaison between LDAC and DHS. Dr. Kramer thanked Mr. James Tucker for attending the meeting and taking notes.

2. Background of Senate Bill 1115

Dr. Kramer discussed the language in SB 1115, passed by the legislature and signed by the Governor in 1999. The bill, introduced by Senator Chesbro, created a Lyme Disease Advisory Committee, and directed DHS to establish an information program on Lyme disease and provide information to the Occupational Safety and Health Standards Board about risk factors for exposure to Lyme disease. To meet these legislative mandates, DHS was allocated funding and one position through the budget change proposal process. Dr. Anne Kjemtrup was hired in August 2000 as a tick-borne disease specialist. She will be responsible for developing the Lyme disease education program

and will organize LDAC meetings. Dr. Kjemtrup is a veterinarian with a Master's degree in preventive veterinary medicine and a Ph.D. in epidemiology. Her research in babesiosis, another tick-borne disease in California, involved tick and small mammal collection, as well as molecular test development. Her research and her medical background are excellent qualifications for the position.

3. DHS Lyme Disease Program

Dr. Kjemtrup provided background information on Lyme disease in California. Lyme disease became reportable in California in 1989. Since then, over 1700 cases have been reported to DHS. The number of cases reported per year has fluctuated, with a high of almost 350 cases in 1990 and a low of approximately 50 cases in 1994. Since 1994, the number of reported cases has increased slightly each year; 87 cases have been reported to date for 2000. As case reporting is the result of passive surveillance, DHS recognizes that this is probably an underestimate of the true number of cases. Although cases have been reported from all over the state, the majority of cases have been reported from North Coastal areas, with other focal areas in the northern Sierra foothills. DHS has also maintained an active and passive surveillance of *Ixodes pacificus* and, when possible, infection status with *Borrelia* spp. To date, *Ixodes pacificus* have been found in all but three counties in California. These counties are Mono, Alpine, and Modoc. *Borrelia burgdorferi* infection has been documented either by culture or IFA in ticks from 39 counties. Other as-of-yet-uncharacterized *Borrelia* spp., have been documented in ticks from three counties: San Luis Obispo, Monterey and Los Angeles. (Dr. Lane has clarified that the newly described *Borrelia bissettii* was first demonstrated in ticks from Del Norte County during the 1980's by Marge Bissett and Dr. Lane has recovered *B. bissettii* numerous times from ticks from Mendocino County.) Dr. Kjemtrup discussed DHS' activity with regard to the new Lyme disease vaccine. Based on a combination of information regarding incidence of human cases, tick activity and tick infection status, DHS created a risk map of California, demonstrating areas of variable risk. This map was intended specifically for a set of guidelines that DHS distributed to health care providers to aid them in advising their clients regarding the appropriateness of receiving the Lyme disease vaccine. DHS has made this information, as well as the Lyme disease information pamphlet, available on DHS' Division of Communicable Disease web site: http://www.dhs.ca.gov/ps/dcdc/html/publicat.htm. Dr. Kjemtrup concluded by saying that she is looking forward to working with the Committee and opened the floor for questions.

Dr. Lane asked for clarification of *Ixodes pacificus* records in Mono County. Dr. Kjemtrup noted that no official collections have been made from that county although the search continues. Dr. Lane also asked if, since Mono County shows apparent high incidence of reported cases, whether the risk map should be modified to show the eastern Sierra as an area of "some" risk. Dr. Kjemtrup replied that historically, Mono County has reported zero to one human case per year and the apparent high

incidence is an artifact of the low population in the county. Dr. Kramer added that the low number of reported cases and the lack of *Ixodes pacificus* records is why that county is designated as low risk.

Ms. Hubbard asked if the cases from Mono County had a history of exposure in that county. Dr. Murray replied that the case reports contain limited historical information.

Ms. Merrill asked Dr. Murray what criteria are used to evaluate cases, and if a database of all reported cases (counted or not) is maintained. Dr. Murray replied that, in order to be counted as a case, the case needs to meet the case definition established in 1990 by the National Surveillance system. This system was designed to bring uniformity to monitoring cases throughout the country, and not to establish diagnoses. Dr. Murray kept a complete database of all case reports through 1996; a partial database is now maintained.

Dr. Stricker asked if DHS does any testing of humans for Lyme disease. Dr. Kramer replied that funds were allocated from the Legislature to DHS from 1989-1991 to develop a Lyme disease surveillance and control program. At that time, diagnostic services were available. Funding was not renewed in 1992. Dr. Lane informed the Committee that he had just received funds from the National Institutes of Health (NIH) to support research on the isolation and characterization of *Borrelia* obtained from skin biopsies from humans in Mendocino County. Dr. Lane noted that, in his study sites, greater than 7 percent of *Borrelia*-infected ticks are infected with *Borrelia bissettii;* thus, he is planning on investigating if people are infected with *B. bissettii.* He further noted that getting approval from the human subjects research committee at U.C. Berkeley and finding a physician who would be willing to do punch biopsies was not an easy task.

Ms. Hubbard asked whether Dr. Lane was interested in obtaining rash (erythema migrans) biopsies from throughout the state. Dr. Lane said that would be ideal, however, finding physicians willing to put themselves on the line with regard to liability issues surrounding punch biopsies was difficult. Ms. Hubbard asked if she could direct physicians willing to perform the procedure to Dr. Lane, and he agreed.

4. Committee Mechanics

a) Election of a Committee Chair: The floor was opened for volunteers or nominations to serve as LDAC Chair. Dr. Kramer explained that the primary responsibilities of the Chair would be to provide input on meeting agendas and to "run" meetings. Dr. Lane volunteered to chair the Committee; there were no other volunteers or nominations. The Committee unanimously voted to have Dr. Lane serve as the LDAC Chair. The Committee thanked Dr. Lane for volunteering.
b) Meeting frequency: Dr. Kramer suggested that the Committee should meet quarterly, especially during this first year as the program develops. Ms. Hubbard

supported this schedule, and the Committee unanimously voted to meet quarterly. The next meeting will be sometime in January 2001.

c) Meeting minutes: It was proposed that minutes of the LDAC meetings be distributed to Committee members via e-mail (when possible) to expedite the process. Committee members will review the minutes and send comments directly to Dr. Kjemtrup within two weeks of receipt. If a member does not provide comments within this time frame, it will be assumed that the minutes are approved as written by that member. Minutes of meetings are confidential until all members have approved them, and should not be distributed until the approval process is complete. Committee members will receive a final version of the minutes as soon as all members approve them. The Committee unanimously voted to accept this proposal.

5. Development of a Mission Statement

For the next hour, Dr. Tayar facilitated the development of a mission statement. The Committee addressed the following questions: Who are we? What do we do? Why do we do it? Who do we do it for? The following draft statement was developed:

> The mission of the Lyme Disease Advisory Committee is to advise and make recommendations to DHS to increase awareness of Lyme disease in California by educating the general public and medical community, in order to minimize exposure to, and suffering from, this disease.

Ms. Hubbard asked if the Committee will focus solely on Lyme disease, or whether the mission will be expanded to include other tick-borne diseases. Dr. Kramer suggested that for now the Committee should focus on Lyme disease and perhaps in one to two years, other tick-borne diseases will be addressed more directly. The Committee agreed. Dr. Morrow wanted to add “and others” after “DHS” in the statement: there was not general consensus on this. It was recognized that this statement needs some refining. Thus, the Committee agreed that members needed to think about the statement some more and send comments to Dr. Kjemtrup. She will incorporate suggestions and send out a revised mission statement for review and approval.

6. Development of short and long-term goals

Dr. Tayar guided the Committee through a process to develop short and long-term goals. Each Committee member wrote suggestions onto cards that were fitted onto a four-year time-line and ultimately sorted into five key categories representing educational and surveillance activities (Figure 1). It was apparent from reviewing the matrix that Committee members agreed that education of the medical community should be a major goal throughout the four-year period. Risk assessment through human case surveillance, tick surveillance, reservoir/sentinel animal surveillance, and diagnostic testing was the second major goal.

This generated a discussion on how best to educate the medical community about Lyme disease in California. Dr. Stricker and Dr. Morrow suggested that an article on Lyme Disease in California could be submitted to the "California Physician," a California Medical Association newsletter. Ms. Hubbard wondered if this kind of article could also be published on DHS' web site. Dr. Kramer said that once approved by the Department, additional information on Lyme disease could be posted. She mentioned that an information pamphlet on Lyme disease is currently on DHS' web site, and acknowledged that one of Dr. Kjemtrup's first tasks will be to update this pamphlet. Ms. Hubbard asked if the Committee would be able to have some input on pamphlet revisions. Dr. Kramer agreed that the revised pamphlet would be sent to the Committee for review before it is finalized. There was also a suggestion that a "frequently asked questions" (FAQ) on Lyme disease be added to the web site. Dr. Kramer replied that FAQs on several tick-borne diseases are currently going through DHS' approval process and should soon be posted on the web.

7. Where to go from here?

Dr. Tayar brought the discussion to a close by noting that the goals listed in the matrix are a "work in progress" and have yet to be finalized by the Committee. Based on Committee comments, she generated a list of action steps:

a) Finalize mission statement
b) Have drafts of educational materials reviewed by LDAC
c) Generate specific strategies to address general goals specified by LDAC (e.g., for medical community education, etc.) Bring specific ideas to next meeting and/or route to Dr. Kjemtrup ahead of time for next meeting's agenda.

The meeting was adjourned at 2:45 p.m. Dr. Kjemtrup will be contacting members regarding their availability to meet in January.

Oct. 24, 2000: Goals that the Lyme Disease Advisory Committee Would Like to See DHS Address

Goal Area	6 months	12 months	18 months	2 years	3 years	4 years
Educate Medical Community	▪ Article in California Medical Association (CMA) newsletter DHS/LDAC	▪ Article in California Physician on LD controversies ▪ Everyone in California (including doctors) will know that Lyme exists in California ▪ Testing guidelines for California	▪ Annual (?) regional tick-borne disease conferences ▪ Educate medical community (seminars, newsletters, CMA/CCLHO) ▪ All licensed physicians in California have been sent information / educational material on LD ▪ Doctors and public will know that current tests do not rule out Lyme disease ▪ Awareness that latency and relapse occur ▪ Doctors and public will be more aware of the myriad of presentations (symptoms) ▪ Physician awareness that long term treatment protocols are necessary until no evidence of symptoms	▪ Physician reporting has improved significantly ▪ California doctors eager to diagnose and report ▪ Proficiency testing for medical doctors in LD	▪ 5% of providers recognize, can diagnose and can treat LD ▪ Physician and public awareness are comparable, and much greater than at present	
Educate General Public	▪ Update brochure (have specific goals) ▪ Establish information network or clearinghouse ▪ Address specific issues (sexual transmission , breastfeeding) ▪ Contact press, initiate good stories on LD	▪ Lyme disease compendium explains DHS's role ▪ Develop public service announcements (PSAs) for a radio		▪ Many areas of risk are posted with information about prevention		
Educate School Children			▪ School education programs so that even school children know about Lyme disease ▪ Tick checks a matter of course in risky areas ▪ Educational stickers designed for general public and school–age children			
Risk Assessment		▪ Regular ongoing surveillance in the population is done and info is given to the public ▪ Protocol for agencies to develop risk / prevention programs ▪ Ongoing research of infectivities in reservoir / sentinel animals ▪ New database of "reported' cases, well funded, detailed, CDC criteria or no	▪ Most public health labs offer tick testing	▪ Develop a Lyme disease program, in-house testing, IFA + culturing; genotyping through UC system ▪ Role of related spirochetes in causing human illness elucidated ▪ Diagnostic tests specific to Bb species / strains ▪ Lab tests are more standardized and more specific ▪ Disease tracking thru lab reporting ▪ Tissue registry / pathology (hoped for outcome of DHS and committee work over time)	▪ Tick studies in every county showing nymphal infectivity rates. I.D. hot spots ▪ Ascertain actual risk by locale (by disease) ▪ Risk factors have been clarified	▪ Quality control of labs
Disease Prevention		▪ Funding for LD Education ▪ Increased awareness such that legislative $$$ available for LD research			▪ Reported incidence has declined markedly	▪ Tick eradication ▪ Tick populations decrease due to widespread use of tick-control methods

Next steps listed:

- Finalize mission statement.
- Have drafts of educational materials reviewed by LDAC.
- Generate specific strategies to address general goals specified by LDAC (e.g., for medical community education, etc.) Bring specific ideas to next meeting and/or route to Anne Kjemtrup ahead of time for next meeting's agenda.